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ABSTRACT

Presented is a model of a graduate course for students from a variety of disciplines on human sexuality and the developmentally disabled. Course objectives are said to include competencies in designing and administering programs to foster appropriate sexual behavior and in assisting parents to deal with their children's sexuality. Seven resources to aid the instructor in facilitating discussion are listed. The course outline consists of six major topics (psychosexual development and overview, attitudinal considerations, institutional and community policies and practices, sex education and remediation, and parental concerns) with associated readings. (CL)

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WORKING PAPER NO. 80

CURRICULUM GUIDE FOR A COURSE ON HUMAN SEXUALITY AND THE DEVELOPMENTALLY DISABLED

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These papers are intended primarily as informal communications to and among members of the Research and Training Center staff. The materials contained herein are generally not in final stages of refinement and are not intended for public release.

Curriculum Guide for a Course on Human Sexuality and the Developmentally Disabled

For many years, problems and issues associated with the sexuality of developmentally disabled persons remained hidden behind a veil of denial by both parents and professionals. Recently, the principle of normalization, aided by court decisions and a general societal shift toward more openness regarding sexual matters, has caused sexuality of the developmentally disabled not only to be recognized, but also to be openly discussed and dealt with. In most instances, however, practitioners are operating in a trial and error manner, unaware of the issues involved and relying mainly on their own good intentions and interpretations of societal norms. To ameliorate some of these deficits in awareness and information, it was decided that a university course should be made available to deal directly with these problems and issues with practitioners-in-training. This paper presents the model used in a graduate course of this nature at the University of Oregon.

The emphasis in this course is on understanding the sexual needs of persons who are developmentally disabled and devising optimal strategies for meeting those needs within the boundaries of societal norms. Professionals from a variety of disciplines who may work directly with the developmentally disabled should be encouraged to participate. Such persons would include special educators, health professionals, physical therapists, psychologists, lawyers, and rehabilitation counselors. The psychological, philosophical, and legal implications with respect to this population and to their families are the foci around which the course develops.

The long-range objective of such training is to provide the student with knowledge of the problems and of the many possible solutions to these problems associated with the sexual behavior of the developmentally disabled. More specifically, students having completed the course should be able to:

a. display an understanding of the socio-cultural, psychological, legal, and personal implications of the issues surrounding this topic.
b. design and administer programs to deal with inappropriate sexual behavior of the developmentally disabled.
c. design and administer programs to foster appropriate sexual behavior of the developmentally disabled.
d. design programs to instruct the developmentally disabled in sex education.
e. assist parents of the developmentally disabled in dealing with the sexuality of their children.
f. discuss the problems of the sexuality of these individuals with other professionals in an informed and rational manner.

At no time should the course purport to provide all of the answers. When working with subject matter as personal and sensitive as this, an understanding of the issues and of the available alternatives is the closest successive approximation to providing answers.

Instructor's Role and Resources

The instructor should be knowledgeable in all facets of this area in order to serve his/her twofold purpose of: (1) being a resource to the

people in the course who may be confronting these issues for the first time, and (2) facilitating the discussion and sharing among students that is inevitable if the course objectives are to be met. Several resources are available to the instructor who may be teaching this course for the first time, and it is recommended that he/she be familiar with them before the first meeting.

Obviously, the instructor should have a thorough understanding of sexuality in general. Because sex remains a personal matter, one often overlooks gaps in knowledge. However, in teaching a course like this, one must be prepared for almost anything, including questions pertaining to "simple" facts about bodily functioning. Since dispelling mythology is one of the purposes of the course, accessibility of accurate information is imperative and nothing should be taken for granted. An excellent book that provides an extensive overview of sexuality in Western civilization is:

Katchadourian, Herant A., & Lunde, Donald T. Fundamentals of human sexuality. New York: Holt, Rinehart and Winston, Inc., 1972.

Topics in this book cover an entire range of sexual considerations, biological, behavioral, and cultural.

A basic grasp of topics traditionally associated with the sexuality of the handicapped is also necessary. SIECUS, the Sex Information and Education Council of the U. S., publishes a useful packet. Included are five of their study guides ("Sex Education," "Homosexuality," "Masturbation," "Sexuality and the Life Cycle," and "Sexual Encounters Between Adults and Children"), three of their special publications (A Resource Guide in Sex Education for the Mentally Retarded, Developing Community Acceptance of Sex Education for the Mentally Retarded, and A Bibliography of Resources

in Sex Education for the Mentally Retarded) as well as three reprinted articles on the subject. The "Resource Guide" and "Community Acceptance" papers are of special relevance. This packet entitled Packet VIII: Sex Education for the Handicapped, is available directly from SIECUS, 1866 Broadway, New York, New York 10823, at a total cost of $6.80.

In addition, the instructor should be aware of the various techniques and cautions relative to running a discussion group on the topic of sexuality. An excellent manual from which many suggestions and ideas can be taken is:

Kempton, W. Guidelines for planning a training course on human sexuality and the retarded. Available from: Planned Parenthood Association of Southeastern Pennsylvania, 1402 Spruce Street, Philadelphia, Pennsylvania 19102.

A small number of films are available that may be used in conjunction with this course. One of the best is:

Like Other People, which is available from: Perennial Education, Inc., 1825 Willow Road, Northfield, Illinois 60093.

Narrated by a cerebral palsied young woman, this film does an excellent job of portraying the human needs of disabled persons and the all too common frustration of those needs.

Films dealing with both sexuality in general and sexuality related to disability are available from: Multi Media Resource Center, 540 Powell Street, San Francisco, California 94108. Since these films may be deemed too explicit for use in some settings, it is advised that they be previewed carefully.

A filmstrip/phonograph record designed for use with parents and professionals is also available. Entitled Sexuality and the Mentally Retarded,

it may be obtained from: Planned Parenthood of Southeastern Pennsylvania, 1402 Spruce Street, Philadelphia, Pennsylvania 19102.

Outline of the Course

Working at the broad level of the topic of sexuality and the developmentally disabled, within the time constraints of a university quarter, eight major topics were chosen in an attempt to provide a comprehensive overview. Efforts were made to sequence the topics so that they formed a logical flow from beginning to end. Following is the outline and readings used, with some comments about possible directions and emphases.

I. PSYCHOSEXUAL DEVELOPMENT AND OVERVIEW

Although everyone claims to "know" all about sex, some elementary facts should be reviewed at the beginning. Included should be a thorough discussion of definitions of developmental disabilities, including labeling and stereotyping, in preparation for the possible ramifications that emerge later in the course. Research pertaining to similarities and differences between the sexual development of developmentally disabled and "normal" persons should also be discussed.

Readings:

Wolfensberger, W., Normalization: The Principle of Normalization in Human Services, Chapter 12, "Meeting the Socio-sexual needs of severely impaired adults." National Institute on Mental Retardation, 1972.

In de la Cruz and LaVeck: John W. Money, "Some Thoughts on Sexual Taboos and the Rights of the Retarded." pp. 3-14. Psychosexual Development and Sex Education. pp. 15-57.

Hammer, S. L., Wright, L. S., and Jensen, D. L. "Sex Education for the Retarded Adolescent: A Survey of Parental Attitudes and Methods of Management in Fifty Adolescent Retardates." Clin. Ped., 6:621-627, 1967.

Mosier, H. D., Grossman, H. J., and Dingman, H. F. "Secondary Sex Development in Mentally Deficient Individuals." Child Development, 1962, 33, 273-286.

Optional Reading:

Katchadourian, Herant A. and Lunde, Donald T., Fundamentals of Human Sexuality, New York: Holt, Rinehart and Winston, Inc., 1972, Part 1, Biology, pp. 23-127.

"Sexuality and the Life Cycle: A Broad Concept of Sexuality" SIECUS, Study Guide No. 8.

II. ATTITUDINAL CONSIDERATIONS

Since this area forms the basis of many of the relevant issues, the instructor should approach both societal and personal attitudes directly and openly. Students should be encouraged to question their own feelings and biases as an aid to their own future decisions.

Readings:

In de la Cruz and LaVeck: Institutional and Community Attitudes, Practices, and Policies (session two). pp. 169-220.

Gordon, Sol. "Missing in Special Education: Sex," Journal of Special Education, 5, #4, Winter, 1971, pp. 351-354.

Gordon, Sol. "Okay, Let's Tell It Like It Is (Instead of Just Making It Look Good)." Journal of Special Education, Vol. 5 #4, Winter, 1971, pp. 379-381.

Friedman, Erwin. "Missing in the Life of the Retarded Individual--Sex: Reflections on Sol Gordon's Paper." Journal of Special Education, 5, #4, Winter, 1971, pp. 365-368.

Balester, Raymond J. "Sex Education: Fact and Fancy." Journal of Special Education, 5, #4, Winter, 1971, pp. 355-357.

Money, John. "Special Sex Education and Cultural Anthropology, with Reference to Mental Deficiency, Physical Deformity, and Urban Ghettos." Journal of Special Education, 5, #4, Winter, 1971, pp. 369-372.

Morgan, M. R. "Attitudes Toward the Sexuality of Handicapped Boys and Girls." Forward Trends, 16, #2, July, 1972, pp. 62-66.

Menolascino, F. J. "Sexual Problems of the Mentally Retarded," Sexual Behavior, September, 1972.

III. INSTITUTIONAL AND COMMUNITY POLICIES AND PRACTICES

It is at this point that some concrete questions begin to be raised. It is often helpful and instructive to ask an institution administrator to participate in this meeting to share some of his experiences. Also, persons such as aides and helpers at institutions should be considered as possible resources, for it is they who deal with the problems on a day-to-day basis.

Readings:

In de la Cruz and LaVeck: Institutional and Community Attitudes, Practices, and Policies (session one), pp. 145-168.

Abbott, J. M., and Ladd, G. M. "Any Reason Why This Mentally Retarded Couple Should Not Be Joined Together." Mental Retardation, 1970, 8, (2), 45-48.

Bowder, J., Spitz, H. H., and Winters, J. J., Jr. "Follow-up of One Retarded Couple's Marriage." Mental Retardation, 9:42-44, December, 1971.

Bass, M. S. "Marriage, Parenthood, and Prevention of Pregnancy." American Journal of Mental Deficiency, 68:318-333, 1963.

Krishef, C. H. "State Laws on Marriage and Sterilization." Mental Retardation, 9:36-39, June 1972.

Christensen, M. T., and Gregg, C. F. Changing Sex Norms in America and Scandinavia. Journal of Marriage and the Family, 32:616-627, November 1970.

V. SEX EDUCATION AND REMEDIATION: ISSUES AND TECHNIQUES

Besides providing information on teaching technologies, a major issue which arises is: to what norms should the developmentally disabled be taught? This is a highly controversial area and may include such areas as premarital sex, masturbation, homosexuality. The instructor must be aware of his own values and be sure that the material is presented in as objective a manner as possible.

Readings:

Brummer, E. R. Sexuality and Mental Retardation, Rehabilitation Research and Training Center in Mental Retardation, Working Paper No. 67.

Bland, J. S., et al. How May the Retarded Be Trained so that Their Sexual Behavior Will Be Generally Acceptable? National Institute on Mental Retardation.

Rosen, Marvin. Conditioning Appropriate Heterosexual Behavior in Mentally and Socially Handicapped Populations. Training School Bulletin, Vol. 66, No. 4, pp. 172-177, February, 1970.

Sparks, H. L., and Younie, W. J. Adult Adjustment of the Mentally Retarded: Implications for Teacher Education. Exceptional Children, 1969, September 5, 13-18.

Floor, L., et al. Socio-Sexual Problems in Mentally Handicapped Females. Training School Bulletin, Vol. 68, No. 2, pp. 106-112, August, 1971.

VII. PARENTAL CONCERNS

Professional efforts to deal with the sexuality of the developmentally disabled are often confounded by parental concerns. The instructor should be prepared to present the parent's point of view, including possible reasons for the fears and confusion as well as methods for dealing with these feelings. It may be helpful to have a parent address the class and discuss with them the concerns generated. Role-playing teaching/counseling sessions with parents may also be helpful.

Readings:

In de la Cruz and LaVeck: Physical and Biological Aspects (session one). pp. 79-110.

Goodman, L., et al. The Parent's Role in Sex Education for the Retarded. Mental Retardation, Vol. 9, No. 1, pp. 43-45, February, 1971.

Kempton, W., et al. Love, Sex, and Birth Control for the Mentally Retarded: A Guide for Parents. Planned Parenthood Association of Southeastern Pennsylvania.